

OUR VOICE

The Newsletter of Autism Network International

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Apologies to all for the tardiness of this second issue. We will have four issues this year, so the third issue will come out fairly close to the second. We may remain a quarterly newsletter in our second year, or we may increase to bimonthly frequency—it depends on how much you, the members and subscribers, send me to print!

We have a new heading beginning with this month's newsletter. It was produced by Trond Larsen of Norway. Trond writes:

I have read Our Voice carefully, and I will comment on it later.

I will later write to Our Voice about the situation for autistics here in Norway. The situation is far from ideal for most of us 3000 here. But my English isn't good enough to explain all situations and circumstances here. I will also try to write about my own experiences, etc.

I'm looking forward to reading about conditions in Norway and about Trond's experiences, and I'm sure others are as well.

I am pleased to be able to include material from two young people in this issue, as well as from adults. The word squares on the cover were contributed by Kyle Persaud, who writes:

I have some word squares for your newsletter. A word square is an arrangement of words arranged in such a way that they read the same horizontally and vertically.

For example: FLAG
LATE
ATOM
GEMS

I have over 100 word squares which I plan to publish into a book with clues. I have not found a publishing company yet. I have enclosed 15 of the word squares that I have.

I am 11 years old and I enjoy the newsletter.

To all the other kids who read "Our Voice": This is your newsletter too. Write to me.

This issue should arrive in your mailbox just before the 1993 International Conference on Autism in Toronto. ANI will have a display booth in the exhibit area, and I hope all of you who are at the conference will stop by our booth. I will also be giving a presentation on Wednesday, July 14th. I hope to see a lot of ANI members there.

Many thanks to everyone who contributed to this issue. Keep those articles coming!

Jim Sinclair, ANI Coordinator

AUTISM AND EMPATHY
by Kathy Lissner

Very often I read in autism literature that autistic people lack empathy, and the various authors of these works cite examples that lead to their belief. Well, I disagree with that viewpoint. As an autistic person, my problem is not *lack* of empathy, but the opposite. I have the tendency to see every point of view and at times be engulfed by it. For example, when I had a neighbor who had multiple personalities, she had several things going on in her life, and being her friend, I wanted to help in the best way possible. What happened was that I would be so caught up in her issues that it affected my moods drastically. How could I not be affected? Even though it was a time of my life when I was looking for a job, and then finding one as a medical transcriptionist, I still was thinking of ways to help her. I had a hard time separating her issues from mine. Very often, her issues and life engulfed how I felt and what I did.

This quality not only leads me to be engulfed by people's issues, it also gives me the advantage of being able to know why people think the way they do. For example, even though I voted for Perot for President, I talked to lots of people who liked Bush and Clinton, and I asked why. When they

told me their reasons why, I understood where they were coming from. I'll ask why they are supporting that candidate, and they tell me why and I understand their reasons because I know that to that person those reasons are legitimate. I may disagree with that person, but I think to myself, I don't have to agree. All I have to do is respect that person and the choice he/she made. Too often people have this attitude of "If you don't agree with me, you're wrong."

Also knowing history, I've read about people who thought or did things a little bit differently and got ridiculed, jailed, or even killed for who they were or what they believed in. Examples range from Andrei Sakharov when he was exiled to Gorki when there was a USSR because of his view on human rights, to the teenaged kid who wants to get good grades instead of going with the crowd to party, do drugs and have sex. Very often it's the so-called "normal" people who lack empathy because many of them don't want to listen to any point of view besides their own. People like me can't help but to get all points of view, and because of that it has made us into empathic and feeling people.

11/7/92

American
waiting in line
being rained on
to vote for President.

Communist
in Red Square
waving red banner
to times that never were.

Kathy Lissner

HOW TO TALK TO AN ABLE-BODIED PERSON

(This article was originally published in *Access, the Publication of the Center for Independent Living of North Florida*. Although it is written to reflect the experience of people with mobility impairments, readers of "Our Voice" may be amused to note the terms used to describe non-disabled people.)

A person is not necessarily of lower intelligence, just because he or she happens to be able-bodied. Nonetheless, many able-bodied people have difficulty with abstract concepts and big words. It is kinder to them if you just don't say anything that might challenge their limitations. Suggested areas to avoid include: *civil rights, barriers, neuromuscular regeneration, wheelchair sports, and employment*. The experience of many disabled persons suggests that the able-bodied have trouble grasping the concepts.

Able-bodied people often speak very loudly, for no apparent reason. It is very rude to say things like, "I can hear just fine" or "I'm not hearing-impaired." Just put your hands over your ears until they go away. (If you can't put your hands over your ears, we suggest you try speaking to them in whispers. This forces them to stop speaking long enough to hear what you say.)

Sometimes able-bodied people appear to have lower social skills. They say sudden, inappropriate things like, "God loves you because you're special," "I gave to the xxxxx telethon," or "My sister was born with one arm." They may ask questions that reveal their less-developed empathy, such as, "When are you going

to be able to walk again?" Remember, they can't help being severely able-bodied, so it is your duty to be kind and help them stay on the subject. Just ignore inappropriate vocalizations until they resume the subject at hand.

Finally, many able-bodied persons can be rude and selfish, and insist that you do things to help them. Because able-bodied persons have less social experience and lower social skills, they often make peremptory demands, such as "You can't do that," or "This is the only way to manage your skin care!" These encounters are your opportunities to reach out to the able-bodied and help them understand that there are choices in every situation. (Able-bodied people, with their low threshold of abstract thought, tend to see only one response to a set of circumstances.) Be polite and speak slowly when you are explaining something to an able-bodied person; often, if they don't understand you the first time, they will be too embarrassed to ask for another explanation.

If you follow these rules and keep up your compassion for the able-bodied, in time our society may become broadminded enough to recognize them as equals. Within their limitation, of course.

MORE ABOUT ABBY
by Karen Reznak

Dear Jim,

I appreciated your editorial. It helped me to clarify a lot of issues that I have been working through in relation to Abby. I would like to tell you about Abby, so you may understand my concerns.

I want to make it clear that I am not a saint for loving and accepting Abby--she is a very lovable and delightful child. Everyone who takes the time to look beyond her unusual behavior falls in love with her personality. Abby is a beautiful person, inside and out. When I read your letters, and other things that have been written by autistics, I feel that many, if not all of you are equally beautiful. Anyway, I don't know how I would react if Abby did not respond to me, or if I felt that she did not care if I was there or not. Abby does respond to me, and I have never felt that I was only a tool to her. I have never doubted her love or her need for me. She has never been able to say "I love you," but she expresses that love. If I tell her that I know that she loves me, she relaxes in my arms.

Abby's autism now rarely manifests itself in disruptive or dangerous behaviors. She just has her own ways of doing things, and needs to relate to people on her own terms. If we have company, she may sit among us and enjoy herself for a while, then she may withdraw and "get herself back together" (her words). Whenever it is possible to let her withdraw, we let her do so (obviously, we cannot let her lie down in the middle of a parking lot for twenty minutes!). She returns from these withdrawals better able to cope with what is going on.

Until recently, Abby showed no interest in other children--only in adults. Lately, she has tried to draw other children into her play, but she has no idea how to do so. It breaks my heart to watch her wistfully watching her younger sister play with her friends, and be unable to join in. We and everyone who works with her are trying to teach her these skills, but it is very slow going. I know that this is progress, but she was happier when she wasn't interested in other children.

Abby has a wry sense of humor, and enjoys laughing at others' antics (she thought it was a riot when I sat on a wet sponge last week). She does not try to provoke laughter on her own. She also has a very strong desire to please me. I have to be careful with this, because she is devastated if she feels that she did not please me. I have to keep my expectations within her abilities, to avoid having her self-esteem plummet.

One thing I have noticed is that the autistic children I know are very fragile emotionally. It is very easy to destroy their sense of self-worth, and extremely difficult to build it up again. There was a teacher at Abby's school who was terrible with autistic children. She pushed the children hard, and had very rigid ways of doing things. Unfortunately, she was the "Speech and Language" specialist, so many of our children were in her class. Abby spent one month with her (we insisted that she be moved into another class), and it took 4 months of intensive effort to get her back up to the level that she had been at before seeing this teacher. Another child spent a year with her 2 years ago and still has not recovered. Since then, we have been very involved in her classroom.

to prevent that from happening again.

Your feelings about being "different" were enlightening. Of course, everyone is different in some way. Abby has a sweetness that is notably lacking in many children. We have never felt deprived by having an autistic child—we wouldn't trade Abby for anything! We have had far more problems dealing with the school system than in dealing with Abby. If she can continue to believe in her worth, she should do well. I have no desire to remove her autism (assuming that is even possible) if it would change who she is. My hope for her

is that she can grow up like you and your friends, to be happy and accepting of who she is.

The difference between giving autistics the skills needed to function in this world and trying to change them into "normal" people can be a very fine line. To grossly simplify, I guess that it would be the difference between trying to teach a child how to dress him/herself, and expecting him/her to *want* to dress him/herself.

Thank you so much for taking the time to correspond with us. Your letters and "Our Voice" have meant a lot to us.

An Algebraic Parable
by Kathy Lissner

One time in Algebra City, Algebra was a positive Number carrying his profoundly retarded son. The Number loved his son, 5757, dearly. When he went to the doctor for an annual checkup, the doctor said that 5757 contracted 4939 disease, a viral disease that can damage the brain severely if the Number who has it gets it as an infant or young child. After the doctor looked 5757 over, he then said softly to the father, "Why do you care for the boy? He will never speak or do anything for himself. Why don't you put him away and live your life?"

The father answered after a minute of equationing or prayer, and said, "I can't. 5757 is my son. The prophet Infinitus said when he was praying on the Number Line, that the goal in life is to learn from it. And whatever we get, regardless of the circumstance, we learn from life. To me the Zero (God) said, 'Learn from 5757, since he like me is helpless in the world of the Finite.' And so I did. 5757 is the gift that the Zero gave me. I want to learn from life and my son will teach me. As the prophet Infinitus says, 'That life is learned from the least likely Numbers and the most unexpected places.' And so I do because I equation every day, and go on."

The doctor looked at the father for a minute and said, "Oh. That's nice," and wrote out a prescription for medicine for 5757, without even understanding a word the father said.

Nobody Nowhere

In a room without windows, in the company of shadows,
You know they won't forget you, they'll take you in.
Emotionally shattered, don't ask if it mattered,
Don't let that upset you, just start again.

In a world under glass, you can watch the world pass,
And nobody can touch you, you think you're safe.
But the wind can blow cold in the depths of your soul,
Where you think nothing can hurt you, till it's too late.

Run till you drop, do you know how to stop,
All the people walk right past you, you wave goodbye,
And they all merely smiled, for you looked like a child,
Never thought that they'd upset you, they saw you cry.

So take advice, don't question the experts,
Don't think twice, you just might listen,
Run and hide to the corners of your mind, alone....
Like a Nobody Nowhere.

Donna Williams

[This is the title poem to Donna's book. I'm told the book is now available in all the countries where ANI has members.]

A LETTER FROM RICHARD ATTFIELD

I autistic am. I did not know this when I was a child by listening to doctors talk about me. Pediatricians said that I was retarded, not intelligent, but I realized I was intelligent when I was asked questions and was discussing the answer with myself. Why was I born only part a person, a person who is incomplete, cannot communicate and has difficulty with people. My difficulties are many. I realized myself my difficulties when I was a very small child.

I was four. I wanted reasons why my friends could talk and I could not. I just would try to understand why the children were not quiet, they did speech have. Sometimes they would play with me. I wanted friends.

I knew why the children friends would not be with me because hopeless was I with making friends. I was sometimes asked questions by everyone. I was sad when the children some did talk and ask what my name was. I just would see what happened, the children did want a reply from me also to friends be. I became frightened when I could not talk. I did listen to the children in play school playing. I did want the children to chatter less because was difficult for me to try to be friends with the children.

I always have different to other children felt. I feel guidance should first try to be provided to friends as everyone treats autistic children as though they are stupid. Different I am but I am not stupid. I can opinions have, think to myself, reason with myself.

I just thought that I was daft because once people said I was retarded I did assume words I would not learn to speak. I daft would feel when I questions could not answer. I was insecure because of people's reaction to me. People did understand not why answers I could first reply not. When I found I never gave up trying to discuss, reason, why I could not talk, then I decided I was intelligent not daft. I was six.

Fortunately I directly was respect given from some friends which did respect you the person I am, whether I had difficulties or not.

I have definitely decided for myself, I am determined to rectify my difficulties. How would you feel if you did choose to learn and people frustrated you. I am equally capable of learning.

I am sad that I cannot always say when knowledge I would be interested to learn. A ridiculous predicament I am in because I want different knowledge.

Myself I want good knowledge, understanding, to have because I found happiness acquiring knowledge.

Questions people first do ask me when I am unable to speak. I try words myself to answer to people but I dread when words I cannot say. I am different when I worry I shake. Questions really frighten me. When someone asks a question they expect a reply and they think I do not understand. I do understand what they say but cannot answer. I am frightened I will reply not at all.

When I was asked questions reply I always would words decide safe were to answer. I did try to trust people, then friends with them I would be. Then dear friends.

Every time I the special friend was with them I was sad because always and always and always questions stupid why did they ask me. Why should I answer stupid questions? I trusted friends to understand I was retarded not. I cannot read easily, words tumble and jumble together, trouble I cannot handle with stupid questions. Appropriate questions would have been easy to answer on the computer and worth the will power to do words on the computer. I now can type with the communicator. I really don't talk good without it and I certainly will not be ignored. I would like everyone to converse with. A decision it is I myself can make personally when I want to. For really an opinion then I can express for

myself, aware that words do people
answer quite easily what is asked.

Words do impress other people,
Words do express what we feel.
Words tell other people what we

think,

This is a person's right to have
an opinion.

I have said that I will try to
decide things for myself, to take
control, ascertain advice about my life.

People reason that I am just a
child but I am not. I get frustrated
when people really decide things for
me. I thought before that I could on
own for myself not decide things
because person would decide things for
me. I often did want myself to decide.
When words I could not say I resent
person did not understand what I
wanted.

I often really think when I will
one day leave school what I would do.
I did decide first I would try to go to
college, really friends try to have,
then questions I would write for them
to answer and I will realize for myself

why dread I do not feel anymore when
someone asks a question.

I would knowledge wish to learn,
I am as interested to learn things as
other people. I editorial have read. I
don't want to be autistic. Traditions
are special. People go to college,
work, people know really why they do
things. I would also like to go to
college and work.

If I find I say. I say what I
think. Everyone opinions we listen to
but my opinion people do not
understand how I feel. I have
difficulty with communication and
relationships with people. Other people
really don't try identical to be to each
person. Every person thinks and feels
differently to other people.

To just be safe with people is
what I would like. I realize I have
difficulty making friends because I
person am autistic. I care I cannot
make friends. Perhaps friends I will
have eventually. One friend to know
how to have a great life.

Cat

Pouncing,
playing,
chewing,
and dropping
dead cricket near
master's feet.

Kiki

Sitting on my chest,
purring,
making me immobile.

Milk and Cereal

In the bowl,
I eat Coco Puffs,
cats jump on table,
put faces in bowl,
to drink.

by Kathy Lissner

An Intercultural Viewpoint on Autism

by Gerald W. Driskill, Ph.D.

Assistant Professor, Speech Communication
University of Arkansas, Little Rock

This paper is about merging two important parts of my life. The first part has to do with my professional career, the other with a personal friend. I will discuss each of these briefly and then present the way my career has helped my relationship with my friend and vice versa.

My career over the last eight years has involved a specialization in understanding intercultural communication. I have been trying to understand the influence of culture on communication. The goal of my work has been to understand how to improve communication when people are from different background cultures. Let me give an example in which employees in a company did not see the influence of culture when it was in fact present. As you might guess, problems arise when people do not realize cultural differences are having an impact.

I have conducted research in an organization that employs immigrants from India and people born in the U.S.A. This research provided me with hands-on experience that convinced me that people do not always see the ways culture can influence communication. In one organization, U.S.-born employees thought that it was best if supervisors let their employees work without being checked on very often. In contrast to this, the immigrants from India felt that a supervisor was not good if he or she did not make regular checks on employees. You can imagine the conflicts that would come up if an Indian supervisor was always checking on an American employee. The American employee would feel the Indian did not trust him or her.

The whole point is simple:
Cultural backgrounds often influence

what we call "best" or "effective" or "good." My career involves trying to understand these influences and help people adjust to one another.

During the past six years I have learned more about autism due to my friendship with a person who is autistic. I first met him as I began the second round of graduate work. I knew little or nothing about autism at the time. I spent the next three years trying to understand better. I continue that pursuit today.

At first my friend Jim did not seem that unusual—at least from my perspective. Granted, I am tolerant of individual differences. Thus, for some his dress (usually casual clothes, often with something purple), his shoulder-length hair, and his directness (he got right to the point about what he thought) may have seemed odd. Still, he was bright and articulate. He had a knack for cutting through to the heart of an issue or a problem. Thus, I really did not pay attention to behaviors that set him apart. Then one day he reported almost being picked up by an ambulance when he "zoned" out at the office. His explanation of the whole experience was part of my initiation into a world that was almost beyond my comprehension. Time would see me learning more and more about this different world.

This brief paper will attempt to reflect on my understanding of this different world—the world of autism. I will explain the ways my understanding of intercultural communication has benefited me in my interactions with Jim. Before I discuss specific benefits, I believe it important to highlight some basic ideas and beliefs that I hold concerning autism.

Basic Ideas about Autism

1) Autism exists along a continuum, yet there are certain identifiable characteristics shared by many people with autism. This observation is critical. For many people, including myself, I did not realize that my friend was autistic. This lack of recognition was due to my ignorance and Jim's good verbal abilities. I knew very little about autism, thus I typically viewed "different" behaviors as simply different. For example, Jim did not make frequent eye contact, yet I was not informed enough to connect this behavior with other behaviors to consider him as autistic. My only knowledge of autism did not include a high-functioning individual in graduate school who could actually assist me with my research. In fact, I might not have ever known the reason for some of his different behaviors if I had not been told.

2) The fact that a person may not be recognized as autistic means that wrong attributions can occur. Autistic behaviors do not always stand out and demand to be labeled as such. Because of this fact, it is not surprising that autistic behaviors may be viewed as "strange" or "stubborn" or "unfriendly." I will discuss more specific problems created by misattribution later in this paper.

3) The fact that autism exists along a continuum also means that the general guidelines I suggest in this article will need to be tailored to individuals. My examples are based on interactions with Jim. Thus, my suggestions may or may not apply directly to your child or friend or spouse. Still, it is my belief that the general principles hold true for most relationships. I will give examples that should be relevant to relationships with high- as well as low-functioning autistics.

4) The diagnostic symptoms of autism are based on certain "norms" of behavior. Such behaviors, as set forth by the DSM III-R, indicate "marked abnormalities" which make clear references to norms. For example, the Autism Society of America refers to such behaviors as "avoiding eye contact, inappropriate attachment to objects, no fear of real dangers, standoffish manner," as symptoms that may indicate autism in a child. Thus, the norms assumed in this behavior include eye contact, a certain amount of attachment to object, fear of real dangers, and not acting standoffish.

5) The norms mentioned in the list of symptoms relate to two different types of behaviors. First there are behaviors that are related to specific cultural norms. For example, eye contact is a behavior valued in some national cultures but not in others. Eye contact in certain cultures (e.g., Thailand, Japan) indicates a lack of respect. If you traveled to Japan and attempted to look a business partner in the eye, it might be considered offensive. However, eye contact in many Western cultures is critical to being viewed as trustworthy. In the U.S.A. I have had people tell me that they do not really believe people who don't look them in the eye.

Second, there are behaviors in the list of symptoms that relate to more universal safety issues that appear to be important to the life of any individual. For example, the fear of real dangers would be important to any person, regardless of culture. The suggestions provided in this paper are aimed at behaviors *not* related to issues like personal safety.

6) The application of intercultural skills and insights is not intended to downplay differences between people with autism and those without it. Intercultural communication seeks to

understand commonalities and manage differences. However, it is critical that the differences be understood as aspects of the relationship that should not be or in some cases cannot be eliminated. For example, with the example of eye contact, if I traveled to Thailand, it would be helpful to know that direct eye contact may be taken as offensive. I would manage this difference by learning other ways that people showed their trust or lack of trust of me. I should not expect the Thai people to stop acting as they do in order to adapt to me.

Application of Intercultural Communication

Various scholars in intercultural communication have developed lists of behaviors and attitudes believed to be essential for effective interactions with someone from a different culture. I have selected from these lists items that I have found to be useful in my interaction with my friend. The examples I use, however, are a composite of ideas taken from ASA definitions and experiences I have had with Jim.

1) Decrease my confidence in my ability to properly interpret non-verbal cues. What does this mean? The truth is that we usually like to feel we know what other people mean by their actions. Staying with our example of eye contact, many Americans feel strongly that they know a lack of eye contact means a person cannot be trusted. As mentioned above, I had one employee of an organization state that he would not trust anyone who could not maintain eye contact. He was confident that such behavior meant deceitfulness.

Many of the behaviors exhibited by autistic people, like people from other cultures, do not carry the same meanings we usually assign to them. Thus, I have found it helpful to

suspend my belief that I know what certain behaviors mean. Let me give two examples.

First, whether low-functioning or high-functioning, people with autism may have times when they "zone out" or in some way make it clear that they are not connecting with the outside world. I recall Jim almost getting hauled into the hospital during one such episode. Typically, if a friend, fellow worker or child curls up in a ball and rocks back and forth, we are sure he/she needs help, probably medical help. However, if I follow the intercultural rule of not being confident about my initial interpretation, I will learn to accept that a different meaning is possible for such behavior. I have learned that when Jim seems to space out or cease being articulate, that he is either feeling overloaded or for some reason does not need the pressure of interacting.

A second example refers to eye contact. I have learned that Jim may not always look me in the eye when I talk to him. I know that his lack of eye contact has to do with autism, not with his honesty. I have learned that Jim is honest by noticing his consistent efforts to tell me what he thinks, etc. Just like my friends from Thailand, his eye contact behavior is different from what I am used to. My temptation is to think he may be hiding something, but I know now not to trust that idea. He does not appear to hide what he thinks or feels.

2) Increase my ability to "hang in" the relationship when things seem uncertain. Related to the above, I have learned to cope with the ambiguity or uncertainty that surrounds interactions. With my confidence about interpreting nonverbals like eye contact decreased, there may be times when I am feeling on shaky ground about what to think

or how to interpret a behavior. Such uncertainty is the reason many individuals flee interactions with those who are of different backgrounds.

For example, initial interactions with an autistic person may mean tolerating or finding some way to deal with "standoffish" behaviors or "resistance to change of routine." The very labels used by ASA provide an interpretation that suggests a person is rejecting you and being stubborn concerning change. I have learned to not interpret these "standoffish" behaviors in this way. I have learned that it is OK to not be certain about the meaning of these behaviors.

For example, there have been times when Jim has said things like, "You know I really do not even need relationships." He speaks of being OK without people and that people usually create more trouble than help. At first, such a statement might cause me to think he does not want a friendship. In time I learned that he desired a friendship and that the value he placed on it was therefore even higher—he wanted it, even though he did not really need it. Thus, I came to value this special kind of affirmation—wanting a relationship that he did not need. I will share more later about the ways Jim expresses affirmation.

3) Aim for optimal communication competence. One notion in communication theory is that people have different levels of communication ability or competence. One idea is that there are three different levels of competence. The highest or desired level is called optimal competence. These three levels are presented below with examples to illustrate each one. Most of us have done or said things that represent each level. Hopefully the examples will help us see ourselves in such a way that we will seek to improve.

A) Minimal competence—individuals are

not very aware of the rules in a system (culture, organization, relationship) to apply them or to coordinate with others. Thus, they are not able to function or operate effectively within the system. For example, an immigrant might not be aware of the organizational rules associated with decision-making. Problems may surface when an American supervisor expects immigrants to negotiate in the decision-making process. If immigrants are unaware of the rule to negotiate, then they are likely to be puzzled when the supervisor gives them low evaluations.

Thus, when interacting with Jim, if I fail to see that he may have different ideas or ways of approaching problems, I may falsely accuse him of certain motives. For example, I have seen times when Jim has been very reluctant to accept visitors into his apartment. In fact, I have never been in his apartment. He says he does not deal well with "intrusions" from strangers or friends. At a minimal level I would tend to think he is not trusting me or anyone. I may even challenge him and demand that if he wants to be my friend, he should trust me more.

Such behavior on my part would be at a minimal level because I am not aware that Jim and I have different norms or ideas about private space. Jim may also be confused by my demands to visit his apartment because his behavior seems normal to him. Thus, whether it is space related to an apartment or rocking behaviors, when operating at a minimal level we may fail to see the reason for our frustration with the different behaviors.

B) Satisfactory competence—individuals are able to operate within the system because they are aware of the rules; however, they are not able to envision alternatives and are thus

limited in their effectiveness to one particular system. In the example involving minimal competence, the American supervisor may only be operating at a satisfactory level. Supervisors may see only one way to go about the decision-making process, i.e., receive input from other employees and negotiate a final decision. This limited view may keep them from recognizing other explanations for the communication behavior of the immigrant.

Satisfactory competence is similar to an ethnocentric or "culturally self-centered" view of communication behavior in that people are not able to see beyond their own culturally-bound rules for interaction. Thus, as in the above example, Jim and I may both be "OK" when interacting with people who believe and act the way we do, but get in trouble when with those who are different. The trouble comes when either autistic or non-autistic people insist that they have the correct or *only* way to communicate.

With Jim, it may occur if I insist that refusing to allow others in his apartment is simply a lack of trust and a sign of not wanting a friendship. There is no other way to interpret this behavior. If I refused to consider other alternatives, I would likely force Jim into a corner. He would have to choose between our friendship and his need for private space. Unfortunately, we force choices between black and white, when other options may be available. Optimal competence is about these other options.

C) Optimal competence—individuals are able to operate within and beyond the system. They know the rules and are able to go beyond or transcend the rules because of their ability to enact alternative communication behaviors. In other words, I can learn to break the rules or make new

rules when the need exists. I would not have to rely solely on what I have learned from my culture or past experiences.

For example, if the immigrant and American-born employees were able to recognize the influence of the communication rules on their interactions, they would be able to adapt, negotiate, or discuss ways to best achieve organizational goals. The supervisor, rather than seeing the immigrant as stubborn or resistant to proper decision-making routines, might discover other ways to receive needed input from the employee. Conversely, if the immigrant were aware of his or her decision-making preferences, he or she might explore with the supervisor ways to adapt.

Similarly, for Jim, I could learn that it is OK that people have different views of private space, that people deal with change in different ways. I would not have to feel threatened, not trusted, or left out of his life. Jim may also be able to understand the reasons individuals may at first view his approach to private space or change as strange or different. He would have to recognize that most folks may misinterpret him and thus, when needed, take time to discuss the misinterpretation with the other. Or, if Jim were not able to talk to the other, someone else may be needed as an advocate.

Of course, at least one challenge needs to be kept in mind in the process of being optimally competent. The other person (autistic or non) may not be open to other ways to interpret an event. In other words, the person interacting with an autistic person may be stuck at a minimal level, and not accept explanations of autistic behavior. Thus, in such cases, it is essential that contact with this person be minimized or avoided.

In short, optimal competence in

communication means that I not only recognize that there are other perspectives and ways of being, but that I also work to show that I consider these other perspectives as valid. Such efforts are not easy. Point four is about some practical ways to move toward optimal competence.

4) To reach toward optimal competence, I have found it important to develop core or central beliefs that will allow for greater flexibility. How can the tasks of decreasing confidence, increasing tolerance for uncertainty, and developing optimal communication competence be reached? There are no short cuts. Beliefs about best ways of interpreting behavior and acting are ingrained. I have, however, found certain ideas in counseling psychology helpful in intercultural interactions. I have slowly developed some core beliefs that allow me to interact in a more effective manner. The path I have walked is rewarding and difficult, yet amazingly simple. Let me explain in relation to Jim.

I have asked myself two basic questions each time I have felt threatened or judgmental in an intercultural or "autistic" interaction. The questions are: a) What really makes me secure (loved, wanted); and b) What really makes me worth something (significant)? I have applied these questions to my own beliefs and found myself putting many culturally-based assumptions on hold. Typically, we link having a sense of security and significance with being comfortable (both in mind and body), knowing we are right, being sure about what we believe, having another confirm our beliefs, etc. These typical assumptions come under assault if you attempt optimal competence in communication.

Let me give an illustration of how I have made rewarding shifts in my beliefs about security and significance. These shifts have

enabled me to incorporate the first three ideas in my interactions with Jim. As I present this illustration, try to imagine yourself in connection with an autistic friend. You may need to change or substitute the behaviors in the example with your own experiences, but try to be honest about your thoughts and feelings. Most importantly, try to be honest about your current beliefs about your own security and significance.

I soon became aware that my new friend, Jim, is autistic. Still, even after six years, I am not at all sure how to distinguish between typical personality differences and autistic behaviors. In part, I have given up on deciding which of Jim's behaviors are due to autism and which may be somewhat related to personality. Yet, even as I decide that it's OK that Jim is not like me, I am challenged from time to time. For example:

I receive a phone call. Jim explains that he will not allow someone to inspect his apartment and thus may end up on the streets. Inside, I react. I feel that he must be stubborn. If I, or most people, were not willing to let an inspector in our apartment, it would be for one of two reasons: The place was a pit and we were too lazy to clean, or we just wanted to create trouble. However, I know that there may be another explanation, however foreign it may seem to me.

What is the other explanation? It is possible that a person may have a different experience of space than I do. A person may have a different set of perceptions about what is essential to his security than I do. Instead of being stubborn or lazy, the person may be genuinely concerned about his well-being.

Such a switch in thought may not happen quickly. It may not even feel "right," since I am having to trust a third explanation that may not ever be true of my experience. I doubt I will ever refuse apartment inspections

unless I am lazy or stubborn! Thus, the key question becomes: "What can motivate me to believe Jim and help housing authorities also believe him?"

I have never met someone with such behaviors. Yet I can apply my two questions about security and significance and come up with the following set of thoughts as I consider the situation:

I feel threatened and a bit insecure interacting with Jim. Right now, I am tempted to challenge him and tell him to stop being stubborn. However, I know this sense of threat comes because I think I have to be right about what is correct behavior. I begin to switch gears. I can be secure on a different basis. I can be secure knowing that I am helping someone deal with his world. It is OK that his beliefs are different from mine. Thus, the thing that makes me secure and significant is knowing that I am trying to understand others and grow with them, not by always being certain of who they are or what they are. Security and significance need not be based on the person's being like me or making me comfortable. Indeed, being open to worlds that are different from mine can bring a new kind of security and significance to my life. I no longer am forced into deciding Jim's behavior based on what I think is best. In a sense I am free to be more empathic with all people.

So whether it is a different need for space, a lack of eye contact, a rigid insistence on a schedule, a preoccupation with an object—none of these behaviors merit my judgment as not normal and as cause for me to flee the person. It may be easier to assume that I know what these behaviors mean based on my usual experiences. However, the ease of interaction in one relationship does not

mean the need to avoid learning ways to interact with this new friend. Let me try to demonstrate the value of such an interaction.

Later I meet again with Jim. He speaks more about the trouble people cause him—I have trouble seeing how he sees it as trouble. He tries to explain. The inspector wants to check out the safety level of his apartment. They want to enter his place a few times over the next month. I would not have trouble with such visits. He calls them intrusions. I feel uncomfortable with his level of anger. His demands to be left alone and to be given more time to prepare for inspection seem unreasonable. Yet, as I listen, I pause to say to myself, "Maybe this person has a different view of what makes him secure...maybe he is not like me concerning the way he deals with change." Can I still be his friend?

I have learned to say "yes" to that question, because learning to have better, more fundamental ideas about what makes me secure and significant has proven worth the effort. Instead of thinking security means being right or comfortable, I have found that security means being helpful and understanding. Instead of thinking significance means having Jim always agree with me or give to me on my terms, it now means seeing the gifts he does bring to our relationship and valuing him on his own terms. In short, a different definition of security and significance frees me from being self-centered or overly concerned with my ways and ideas being right.

In conclusion, I have found that interactions with my autistic friend, as with friends from different cultures, are rewarding. Obtaining these rewards has been aided, in my case, by applying a few guides found in the intercultural literature. Let me summarize these: (1) Decrease my confidence in my ability to properly interpret non-verbal cues; (2) Increase

my ability to "hang in" the relationship when things seem uncertain; (3) Aim for optimal communication competence; and (4) Develop core or central beliefs about security and significance that will allow for greater flexibility.

The benefits of applying these guides are many. I will close by stating a few. Hopefully, many of you can identify with these rewards, and if not, I hope you will be able to do so in time.

First, I find that Jim makes me rethink my ideas about what is most important in relationships. Your experiences may differ. Yet, if your autistic child or friend ever has times of appearing distant or disinterested in you, I bet we have faced similar challenges.

I am challenged to redefine what is core and central regarding my own security and worth as a person. This process of redefinition enables me to enact the behaviors that result in improving the relationship with him and others. For example, I am much more open to listening to others, giving them space to be who they are. In short, I do not have to define a good relationship as one in which the person is easy to understand and responsive in ways with which I am most comfortable.

One important relationship that has been helped has been my marriage. My new wife is not like me. I have learned to like our different approaches to time and space. She likes definite times and dates for most things. I enjoy a minimal amount of planning. When our ways come in conflict, I find that I am more accepting of her needs, more willing to find alternative ways. And perhaps, most importantly, more willing to see her approach as of equal importance to my own.

Second, Jim has been part of helping me appreciate diversity in life in all forms. He has a special knack

for understanding and valuing life, from assisting stray pets & injured wildlife to working with autistic children. It is not that I do not have other friends with compassionate hearts. However, with Jim such compassion stands out because it is obvious that all the obstacles he encounters with his autism have not kept him from caring.

He has shown his care for me in ways that are sometimes different than my other friends. Other friends may provide more eye contact or a hug. For Jim, the message of concern for me comes in such things as questions he may ask about a family member that I have expressed concern about. The concern is there in his trust as he has shared frustrations with a non-supportive social system (not prepared to help autistic people). He has told stories about his care for his closest friends—his pet dogs and cats. And, beyond anything he has said, the affirmation has come as he has taken time to walk with me and made every effort to understand my world, even though it is very different from his.

No doubt many of you cannot list the same pluses that I have come to appreciate. Still, I encourage you to list the contributions you do see.

In all, I hope I have given you some feel for what has helped me, and what I have gained from an "autistic friendship." Again, I know that your relationship with an autistic child, spouse, or friend may be very different from what I have expressed. Jim is more verbal than many autistics. Nonetheless, many of the behaviors I have discussed in this article cut across the different levels of functioning. I trust that you will still find a way to apply the basic principles presented.

The autistic world may be worlds apart from that of the non-autistic, but it is my conviction that two worlds together are better than one.

I May Not See You

I may not see you when you smile at me
I may not see your face through all the spinning shapes and crashing colors
I may not know you're there
I may not see you

but if I do
I'll see the rainbows in your heart
I'll see the sun behind your eyes
I'll see the world within your smile
and it will be the most wondrous thing I know
to know that there is such a thing as you within the world I see.

I may not hear you when you call my name
I may not hear your voice through all the whirling noise and swirling echoes
I may not know you're there
I may not hear you

but if I do
I'll hear the weave of your words
I'll feel the shape of your thoughts
I'll ride the flow of your voice
and it will be the most wondrous thing I know
to hear that there is such a thing as you inside the world I know.

I may not feel you when you take my hand
I may not feel your touch through all the edges and vibrations
I may not know you're there
I may not feel you

but if I do
I'll hear the ocean in your heartbeat
I'll feel the earth move in your breathing
I'll trace the fountains of your feelings
and it will be the most wondrous thing I know
to find that there is such a world as you out in the world near me.

I may not know you when you cross my path
I may not find your being through all the scattered bits and pieces
I may not know you're there
I may not know you

but if I do
I'll know you outside space
I'll know you beyond time
I'll make a world for you alone
and it will be the most wondrous thing I know
to know that there is such a thing as you here in the world with me.

Jim Sinclair

**BONE THINGS WHICH WORK AND SOME WHICH DON'T
AND WHY I'M HAPPY BEING AUTISTIC**
by Lawrie Horner

When I was 17 I was diagnosed as so acutely schizophrenic that I was put in a psychiatric hospital, with no likelihood of ever leaving. My treatment there was large doses of the antipsychotic Stelazine, and ECT.

Neither did the slightest good. I've found that I'm very prone to side effects with high doses of neuroleptics. The ECT meant that I lost most of my memory of my early life, and this didn't come back to me until the end of my first years at university when I was 21. I spent each evening getting stoned. Dope is bad for me as it makes me more nervous, and this was compounded by the memories which the dope brought back. However I think that I'm entitled to my own memories, however bad they may be.

Between the ages of 21 and 33 I went to a series of psychotherapists. That didn't help either. "Insight-oriented psychotherapy" seems to be of little use to people with autism, and it can be positively harmful for those with psychiatric disorders. Insight-oriented therapy relates everything to childhood conflicts. This type of focusing just made me more angry, tense and depressed, aggravating the boozing and screaming nightmares. It doesn't take into account the possibility that someone may have a disorder of the brain rather than the mind. A few examples: Sheldon Kopp, in his otherwise excellent *If You Meet the Buddha on the Road Kill Him*, states clearly that he sees psychosis as a cop-out from psychotherapy. English funny man John Cleese wrote *Families and How to Survive Them* with a very experienced psychiatrist, and they put autism down to some obscure early childhood bonding problem.

Psychotherapists became increasingly irritated at my apparent

refusal to get better. I took this on board, and came to see myself as so despicable that I couldn't even say, do or think the "right" thing in a counseling session. The psychotherapeutic model contributed greatly to my lack of self-esteem.

To give the psychotherapists their due, there was good material to work on. I think it was Tolstoy who said that all happy families are happy in the same way, but that all unhappy families have their own way of being unhappy. My parents certainly chose their own way. They had rationalized their neuroses into a literary format, which was visited on me from an early age.

My father's view was that he and I were tortured artists whom women would never understand and who would never be happy. He used to talk at me about Stephen Dedalus in *Portrait of The Artist as a Young Man* and Jude in *Jude The Obscure*. "God how he suffered!" my father told me repeatedly. My mother used the Brontes as her inspiration. All women were like the Bronte sisters, passed over in favor of their egotistical male siblings, but underneath possessed of the most staggering courage and ability. All men were like Branwell Bronte, indulged and ultimately hopeless. "No woman would ever marry you," my mother told me, frequently, with cold vindictive anger.

I left Perth, in Western Australia, to get away from my family, and managed to get into arts administration. I ended up as Activities Director at a major Melbourne university. In a fit of depression and rage I wrote my parents a huge letter, saying how much I hated them and wanted to have nothing to do with them ever again.

When I was 33 my psychotherapist had me see a psychiatrist, the Professor of Psychological Medicine at a major Australian university. He sat behind a large desk with the sunlight coming in the window behind him, so that I could only see him as a shadow. At our second meeting he said that I was a borderline schizophrenic with no chance of improving, that I was a very difficult person anyway and that the best I could hope for was not to become totally insane. He gave me a prescription and said goodbye. I went home and wept. Now I hold him in great contempt. It should be obvious to even the most autistic of us that this approach serves the doctor's ego and not the client's needs. The fool airily dismissed my concerns at side effects.

I became totally over-medicated, falling asleep everywhere including at my work as Activities Director, and unable to remember anything. At work I was torn to shreds at a lunch for my staff at which my boss presided. I was told that my contract would not be renewed.

It is obvious in looking back that I should have gotten a second opinion and that I should have monitored the medication. In fact it wasn't until years later that I connected my bizarre behavior with the medication. I was blaming it all on my unresolved childhood feelings. It is undeniable, though, that I caused much suffering to my staff and colleagues and I bitterly regret this. I had responsibilities which I refused to acknowledge.

The high point in that terrible period was knowing a student who was also a member of the Union Board, Donna Williams. This is the period which Donna describes in *Nobody Nowhere*, talking about her friendship with Bryn. Donna and I rambled at each other over lunch on the

university lawns. Yes, we had lunch under a special tree, just as she describes it in the book. I should point out that there was no affair. At the risk of sounding like a newspaper, Donna and I are just good friends and always were.

University Counselling Services referred me to a psychiatrist whom I still see. David was quite different. With his gray beard, jeans and runners he looks like a jazz musician in his 50s. He puts his feet up on his coffee table and laughs uproariously at my off jokes.

I managed to get a job in health/welfare, and this showed me how unusual David is as a doctor, and how prompt he was in changing medication. Other doctors might have taken weeks, conferring with my previous consultant, and agreeing with his diagnosis for political reasons. David put me on antidepressants and took me off the other medication straight away. He didn't bother with psychoanalysis. He simply gave me everyday tips and advice. (I clarified with him recently that he used this technique because he thought I was schizophrenic.) That was the turning point. I started to see things about dealing with people, instead of being told to focus on my feelings of anger towards my parents.

Working in health/welfare gave me some insights into why I was no good in psychotherapy. I simply don't have much in common with most psychotherapists. They seem to have a veneer of warmth and fuzziness, but underlying social snobbery and patronizing attitudes to their clients. I was stunned and then infuriated to see that the "service delivery staff" had no *empathy* with their clients. Case discussions showed again and again that they applied the standard techniques, dismissed clients as unworkable if the results didn't come, and made decisions based on office politics. One social worker was

different. She saw clearly that clients were put off and intimidated by upper-middle class and patronizing arrogance. She rode a huge bike, put her feet up on her desk and smoked roll-your-owns. She only survived because she got results and knew how to guard herself against office politics. I was extremely bad in my dealings with the staff. However I did very well with a number of very difficult clients. I also did well with--dare I say it--"ordinary working class" people who had problems that needed fixing. Amongst the clientele of intellectually-disabled clients I was one of the most popular staff. I didn't patronize them.

David mistakenly had me attend a psychodrama group. I lasted about 6 sessions before flatly refusing to go back. I have strong views on group therapy, just as I do on psychoanalysis. If you have troubles with social matters the hardest thing of all is some kind of group therapy, where the rules are bizarre and based on unusual interpretations of social interaction. My view of psychodrama is that the ones who learn to play the rules win and the ones who are too nervous lose. It's also a perfect setting for group politics to build up against someone who doesn't cry enough or cries too much or some damn thing. Forget group therapy!

Some years later, after I was on medication, I resolved things with my parents. I respect the effort they've put into resolving their problems, and I like them well enough. However, I prefer to keep my feelings for my partner Robin, my writings, my friends including Donna and the other things that are important to me.

The breakthrough came in March 1992. A courier delivered a parcel and I vaguely remembered the writing. Inside was a presentation copy of

Nobody Nowhere. This threw me into utter confusion, but it established several things in my mind. I contacted my long-lost friend Donna Williams. We talked for up to 18 hours at a stretch. Never have I been able to talk to someone in that fashion, and never have I met someone who seemed to be so like me. Donna served as an example for me, and still does.

My first move was to contact David, whom I hadn't seen for several years. I told him about having Conversations In the Head and other thought disorders, and tentatively suggested that I was in fact a borderline schizophrenic. He simply laughed and said: "What makes you think you had me fooled?" He started me on a very small dose of Stellazine, and it is very helpful in controlling problem thoughts. I had a bitter argument with him--it had required me to go back and diagnose myself rather than his belief in a diagnosis he had privately made nearly 6 years before. He agreed that "it seems a pity" that he hadn't bitten the bullet. Still, at least I can say that I had a shrink too frightened to speak! David felt--and still feels--that I am a kind of schizophrenic. He accepted that I might have Asperger syndrome, but felt that was simply a new name for a set of psychiatric symptoms which had already been recognized and documented.

Meanwhile I waited several months for Dr. Lawrie Bartak, one of Australia's autism experts, to return from overseas. Lawrie saw Donna for a year, and they are good friends. Lawrie believes that I have mild Asperger syndrome. I got a second opinion from a psychiatrist colleague of Lawrie's, an eccentric faded hippy who specializes in autism and whom I immediately liked. He felt that I have mild Asperger syndrome and elements of schizophrenia. I'm happy with that, at least until some research is carried

out on "pseudo-hallucinations" and thought disorders in Asperger syndrome.

David now acknowledges that there could be interpretations other than schizophrenia for what I have, and he was interested to read a copy of *Autism and Asperger Syndrome* which I lent him. In fairness to David he has easily come to accept a disorder which he knew nothing about, and it should also be said that high-functioning autism is rare enough that the suburban psychiatrist is unlikely ever to come across it.

Medication. I find Tryptanorl very helpful, partly as an antidepressant and partly because it acts as a sedative. The small doses of Stellazine exert some control over my thought disorders. David is looking at more modern neuroleptics, in the hope that one will get rid of the Conversations in The Head. I'm not certain that this is going to work, but I'm happy to give the idea a try.

From my correspondence with Donna it seems that a number of Asperger syndrome people have Conversations in The Head, although not necessarily as violent and paranoid as mine, and it could be an autism feature which does not respond to antipsychotics. However, I also gather that small doses of antipsychotics can be helpful for autistic people, since low doses act as anti-anxiety agents.

Social matters present yet another problem. I find it very hard to read how people are thinking and feeling, and the most likely interpretation I can place on their behavior is that they are angry with me. This has certainly been so in the past, when I behaved very aggressively, pushing my ideas down people's throats and refusing to tolerate anyone who I felt was a fool. I see now that my behavior was prompted in part by feeling alienated—I could not understand why

others seemed to get along well and with so little effort, why they seemed to grasp effortlessly the endless subtle social conventions at which I could hardly guess.

I find the most difficult social situations are those where I have different relationships with different people, where some people know each other and others don't, where there is no formal activity and so I have to respond as best I can to the utterly confusing social cues, where there is some sense of occasion and everyone is in a sense acting up to that occasion. A perfect example is a cocktail party. I can say for a fact that I get more, socially, from a visit to the dentist than from organized social events. But if you spoke to my dentist he'd probably tell you that I'm so at ease when he's drilling away that I must be quite brilliant at a "real" social occasion!

I've learnt a couple of things about social events.

One is not to try and do more than I really can. This means that I hang round in the background and chat briefly with one or two people as they go past, and I don't bother trying to be part of a group. I try to ignore the bizarre impressions that people give me socially—the facial and vocal contortions, the sudden moves of eye, gesture and head which they do so easily and which strike me as so sudden and confusing. I try not to get fixated on people's hands, waving so distractingly and strangely. I find the hardest thing is to avoid getting paranoid. I always get the impression that everyone is watching me fumbling away in the background and that everyone is talking about me. They may be, of course.

One activity which I used to try at parties was to go to another room, read a book and get quietly and solitarily off my face. Being drunk improves the self-confidence but makes

the play even harder to read.

It's been a difficult transition for me, because I sometimes used to be seen as an outrageous party entertainer, the one could down a few and say the most daring things without a second thought. This sort of thing used to aggravate my nervousness no end, and I'd spend all night having nightmares and grinding my teeth.

Another thing I've learnt is that it doesn't really matter. I have my friends, and I have my interests, and these are good enough for me. I don't have to do the "right thing" socially, for fear of being told that I'm not working through my childhood feelings.

I shall be seeing Lawrie Bartak for a few sessions before long, and I think I'll be able to get a few tips from him.

I think that if you have autism and no other disorder, the best thing is some counseling in everyday living skills. You can't "cure" autism and there's no reason why you should try. It's part of you. If you have a psychiatric disorder too then the best thing is the lowest possible dose of an appropriate medication. It's trial and error with antipsychotic drugs, and finding out about them can be an endless source of fascination to some people with high-functioning autism. That's part of you, too. It may also be possible for some autistic people to do all right on small doses of neuroleptics, as an anti-anxiety agent.

Having a label—well, two labels—confers great freedom on me. I don't have to feel I've let myself down and been gutless if I'm not the life

and soul of the party. I also feel that I belong somewhere. These are things which Donna pointed out when interviewed on Australia's Radio National after *Nobody Nowhere* came out. I can try to accept that this is just the way I am. It's part of me too. I can start to respect myself.

I hope these thoughts are of some interest to people out there.

And another thing. I can indulge my passions for phone numbers, maps and military ranks. I don't have to get angry about my parents publicly ridiculing me over these harmless interests and I don't have to have some well-paid idiot relating them to unresolved childhood feelings.

Do you know that the shortest phone number in Australia is a local call to the Sydney Opera House and some local calls in the rural city of Geelong? They are only 5 digits, whereas all other major city numbers have 7 digits and all other rural numbers have 6 digits. And do you know that only one country town has a 9-digit area code? It's the only manual exchange left in Australia. Also, I'm told that in the US there is one 3-digit prefix which is used only in movies and TV shows. This is so thousands of clever kids won't work out the number from the time taken to dial and call some poor local unfortunate believing that they've got Bill or Ted with their excellent or bogus adventure.

I'm not a tortured artist I'm a tortured autist.

[Editor's note: Lawrie's story illustrates the confusion that sometimes still exists between autism and schizophrenia. Thought disorders, hallucinations and delusions are *not* characteristic of autism. According to DSM III-R, if a person is autistic, that person can be given an additional diagnosis of schizophrenia *only* if he or she also has prominent delusions or hallucinations.]

MORE THOUGHTS ABOUT AUTISTIC PEOPLE AND ABUSE
by Jim Sinclair

In the last issue Kathy Lissner wrote about sexual abuse of autistic people. Vulnerability to abuse is a serious problem for any disempowered group, but autistic people are particularly at risk because certain typical characteristics of autistic people make them especially vulnerable to typical behaviors of abusers. In this article I will suggest some ways autistic people can protect themselves from abuse by learning to recognize abusive behaviors, and by learning to make themselves less vulnerable to victimization.

As Kathy mentioned in her article, autistic people often have little or no comprehension of nonverbal behavior, including facial expressions, gestures, and vocal cues. This makes it more difficult for us to pick up on cues that most people would recognize as danger signals. With some abusers that doesn't matter; many abusive people are very skilled at presenting themselves in a way that wins the trust even of people with normal communication skills. But some abusive people have borderline social skills themselves, and prey on people who are even more socially impaired than they are. Autistic people should try to become as aware as possible of nonverbal danger cues. Friends or family members may be able to help develop this awareness, by pointing out and explaining nonverbal signals used by themselves and others.

It can also be helpful to watch movies or television programs and attend carefully to the nonverbal behavior of the actors, and perhaps ask a non-autistic friend to watch with you and discuss the nonverbal communication. I've found that using videotapes is much more illuminating than watching a movie at a theater or watching a television program straight through as it's being broadcast. With a videotape I can stop and replay a scene as many times as necessary to be sure I've seen everything. I can

go back and replay earlier scenes after I've seen what happens later, to see if I can pick up on any cues I missed before. Sometimes if I sense that a certain interaction between characters is especially important, I'll replay the same few seconds five or six times or more, so I can catch every word and watch each character's face and body language.

Watching a number of programs that deal with issues such as domestic violence, acquaintance rape, or stalking can be helpful in identifying common patterns. Even though they're intended for younger people, I've found that many "CBS Schoolbreak Special" programs present important topics in a way that I can follow.

One special issue that I would *strongly* encourage autistic people to familiarize themselves with is alcohol and drug abuse. I got into a very bad situation with an alcoholic simply because I didn't know how to recognize when a person is drunk. People who are under the influence of alcohol or drugs often behave in unpredictable and dangerous ways. According to statistics I requested from various social service agencies, alcohol is involved in at least 50% and possibly as many as 90% of all domestic abuse and rape cases.

Another common characteristic that puts autistic people at risk is that we tend to interpret language very literally and to believe whatever we are told, even if we are told contradictory things. This makes it easier for abusive people to trick, confuse, or intimidate us so that we don't protect ourselves or escape from the abusive situation. Habitually abusive people are masters of deception. They lie continually—sometimes plausibly, just to cover their tracks, and sometimes outrageously, to keep their victims confused and disoriented. An abuser might say one thing one day and then the next day say just the opposite, might say things

didn't happen when the victim remembers perfectly well that they did happen, or might make up stories and insist that things did happen when the victim knows they didn't. Under this kind of psychological guerrilla warfare even normal people often start to believe they're going crazy. If someone tells you one or two things that seem contradictory or confusing, it's probably best to explain your confusion to the person and ask for clarification. It might be an honest misunderstanding. But if someone *consistently* tells you things that don't make sense, and especially if the person then tries to make you believe that you can't trust your own knowledge and memories, you should consider the possibility that the person is lying or trying to confuse you.

One of the simplest but most dangerous things abusive people say is, "I won't do it again." There is a pattern known as the "cycle of violence" that many abusive relationships follow. (The cycle of violence is most often discussed in connection with men who abuse their wives or girlfriends, but it can occur in any type of relationship and regardless of the sex of the victim and perpetrator.) At the beginning of the cycle things seem very, very good. The person isn't acting abusive at all; on the contrary, he or she acts very loving, supportive, and understanding. Then tension starts building up. The person may become very critical or short-tempered, or may become remote and emotionally unavailable for no apparent reason. Then there's the outburst. It may involve physical violence, verbal attack, or destruction of possessions, but whatever form it takes, it's an attack calculated to hurt and terrorize the victim wherever he or she is most vulnerable. After each outburst, the abuser is very apologetic and contrite. He or she may shower the victim with cards and gifts, cry and beg for forgiveness, say that he or she loves the victim and cannot live without him or her, promise to do anything the victim asks if the victim

will only give him or her another chance, and of course, promise never to be abusive again. If the victim is persuaded to give the abuser another chance, the abuser usually does treat the victim very well for a while, the way he or she did before the abuse began. But this is a repeating cycle--the abuse *will* happen again. Always. Some abusive people can change their behavior through intensive, long-term therapy, but the chances aren't very good even then. Abusive people do not stop being abusive just because they promise to stop or because they seem to get better for a while after an abuse episode. If someone in your life is following this pattern, you should contact a domestic violence agency for information and help.

Another way abusers distort truth is by making unrealistic threats to keep victims from leaving or reporting the abuse. Threats against family and friends are common. Abusers may say they're going to physically hurt or kill people, or they may threaten other kinds of harm. For example, when I was little an older child in my neighborhood used to tell me that if I didn't do what she wanted me to, she would tell "the man who owned our block" to take away my family's house, or she would make my father lose his job. Of course these threats were ridiculous, but I had no way of knowing she couldn't really do the things she threatened. Since autistic people often lack practical knowledge about how social institutions operate, it's harder for us to recognize if a threat is unrealistic. If someone threatens an autistic person, the autistic person should immediately report the threat to a trusted friend or family member to find out if there really is cause for concern, and what can be done about it.

This is important even if--*especially* if--the abuser has threatened to do some harm if the autistic person tells anyone. A threat that "you'd better not tell, or else" is a clear sign that something wrong is happening. The person who is doing

the wrong thing will do anything he or she can think of, including make threats, to keep people from reporting him or her. Very often these kinds of threats are unfounded.

A threat of violence should *always* be taken seriously, but this does *not* mean the person being threatened should refrain from reporting the situation. A person who's threatening to hurt you if you tell is probably going to hurt you anyway, even if you don't tell. The best thing to do is to report the threat to the proper authorities and to ask for protection, such as a restraining order ordering the person to stay away from you. If you have reason to believe you're still in danger, go to a safe place where the abusive person can't find you. You might go stay with friends or family for a while, if the abuser doesn't know where your friends or family members live. Most cities have shelters where abuse victims can stay temporarily while they receive information and counseling to help them put their lives back together. Information about shelters and other resources is available by calling your local domestic violence agency, telephone crisis hotline, or police department.

I keep recommending that people discuss concerns about abuse with someone they trust, but this is a special problem when it's a trusted person who is being abusive. Autistic people have trouble learning and understanding social conventions, and are easily confused or misled about what is generally considered acceptable behavior. This makes it easier for abusive people to trick us into believing that abusive behavior is all right, or even that it's a sign of caring and love. I was sexually abused by someone who tried to convince me that it was *my* fault: that there was something wrong with *me* for not wanting sex in the first place. Abusers typically claim that what they're doing is "no big deal," that "everybody does it," or that they're treating the victim better than anyone

else would.

The last claim is especially destructive—an abuser tells a victim that the victim is *lucky* to have the abuser in his or her life, because the victim is so dumb, fat, ugly, or otherwise undesirable that no one else would put up with him or her. Often this is accompanied by attempts to isolate the victim from contact with other friends and family. The abuser might tell the victim that friends and family don't really care about him or her, might say things to make the victim distrust friends and family, or might even keep track of everywhere the victim goes and become violently upset if the victim goes anywhere or sees anyone without the abuser's permission. This pattern is another clear sign of abuse. If someone is doing these things to you while telling you that he or she is your friend and is the only one who cares about you, I recommend cutting off all contact with that person. Someone who really cares about you will want you to have a healthy support system, and will not try to destroy your self-esteem.

It may seem counterintuitive at first, but I believe that autistic people who don't like to be touched are at especially high risk of being sexually abused. A person who has always enjoyed being hugged and cuddled by loved ones is better prepared to recognize the difference between healthy affectionate touching ("This is what I'm used to doing with my family. It feels nice.") and actual or attempted sexual abuse ("My family never does *this* to me! I don't like it."). This distinction is much harder to make if a person finds all touching unpleasant. One might still expect that tactile defensive autistic people would avoid sexual abuse simply by refusing all touching of any kind. But as children many of us have been subjected to forced touching, either in the name of formal treatment ("Holding Therapy"), or just by parents and teachers who believe that they are expressing affection and helping the child learn about human contact. Of course, what

this really teaches the child is that he or she has no control over being touched, and that it's wrong to resist touching. Those of us who have been conditioned not to resist unwanted touching are more likely to be passive and unresisting in the face of abuse.

It is imperative that *everyone*--autistic people and those who live and work with them--understand that people's bodies are their own private property. A person who is unable to care for him- or herself may need to be touched by people providing personal care, and a person who has tantrums and is out of control may need to be restrained until he or she calms down, but apart from special cases like those, a person who doesn't like to be touched has the right not to be touched. People also have the right to decide they're willing to be touched by some people but not by others, at some times but not at other times, in some ways but not in other ways. If someone tries to tell you that you "need" to be touched in ways that don't feel right to you, or that there's something wrong with you for refusing, that person is trespassing on your personal boundaries. No matter what you may have been told by misguided people in the past, decisions about who touches you and how you are touched are entirely *yours* to make.

If an autistic person is being or has been abused, it is often difficult for us to recognize the need to report the situation, and to determine how and to whom it should be reported. When autistic people talk about things that are bothering us, the reports are often vague, incomplete, or filled with extraneous details and digressions. This makes it likely that abuse reports made by autistic people will be dismissed or not even recognized as being reports of abuse, because we may not know how to determine which information needs to be reported.

Autistic people also have trouble responding to vague or indirect questions, so if questioning is not precise enough, important information may be left out.

If you think you may need to make a report of abuse, a good first step is to write down the things you're concerned about, making a list of all incidents of behavior you think might be abuse to be sure you don't forget anything. At this point it's probably a good idea to go over your list with someone who is familiar with abuse issues, such as a counselor at an agency that works with abuse victims. The counselor can ask you for additional information that you may have left out but that the authorities will need to know. The counselor can also explain the appropriate reporting procedures in your city. If you're concerned that you might not be able to communicate effectively during a police interview, you can have a friend or a person from the abuse agency go with you to make the report. However, even if you have an advocate with you, it will still be up to *you* to make the report. If the police and the court think that someone else is influencing what you say, your report will be taken less seriously.

Awareness is the best protection against abuse. Autistic people can reduce their risk of becoming victims by being aware of their rights, by learning to communicate their boundaries, and by learning to recognize abusive behavior. Families and friends can help autistic people learn about these things by discussing these issues openly (ignoring them will *not* make them go away), and by providing examples of healthy relationships. Life will never be entirely without risk, but if we work together, we can do much to improve our own safety and the safety of those we care about.

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